

Health Seeking Behaviour of HIV/AIDS Infected Children: A Case Study in Bellary District, Karnataka

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ABSTRACT: *The HIV/ AIDS epidemic remains a serious global challenge and continues to take its toll particularly among vulnerable populations such as children. It is redefining the very meaning of childhood for millions, depriving children of many of their human rights – of the care, love, and affection of their parents, of their teachers; of education and options for the future; of protection against exploitation and abuse.*

This paper seeks to understand the health seeking behaviour of this vulnerable section of the society. It examines their socio-economic conditions and health problems and assesses the care and support available to this segment of the population. It is confined to the 100 HIV infected children who come in the purview of The Nithya Jeevana Network of Positives an NGO which is implementing the national pediatric HIV/AIDS initiative in Bellary, District of Karnataka.

I. INTRODUCTION

HIV/AIDS is not only a health problem but also an overall developmental problem for the society. Though the history of HIV/AIDS is only of 25 years, the damage it has inflicted on the mankind has been appalling and overwhelming. Now HIV/AIDS has become the first truly “International epidemic” easily crossing oceans and border. Both developed and underdeveloped countries have been adversely affected by this disease.

India has the largest number of AIDS orphans of any country in the world. This number is expected to more than double in five years, and the proportion of orphaned children will remain exceptionally high until 2020 and 2030. Given the long incubation period between infection and the onset of symptoms, the epidemic's impact will longer for the decades even if the rate of new infections is brought under control as per the World Bank Report.

Global trends relating to HIV/AIDS

This epidemic sweeping the world cuts across the conventional boundaries of the nationality, race, sex and age. AIDS virus has infected men, women and the children in the developed as well as developing countries. The first diagnosed case is reported from USA in 1981, earlier cases were found by retrospective analysis to have occurred in 1978 in USA and late 1970s in equatorial African regions.

Globally 24.8 million people have died from AIDS since the beginning of the epidemic. According to the Report on the Global Epidemic, July 2009 UNAIDS worldwide approximately twelve of every 1000 adults aged 15 to 49 are HIV infected people. Approximately 50% of adults living with HIV/AIDS worldwide are women. The number of people living with HIV rose from around 8 million in 1990 to 33 million by the end of the 2009. But in the recent years the number of new infections has steadily decline due to the significant increase in people receiving Anti Retroviral Therapy. Around 68 percent of all the people living with HIV residing in Sub Saharan Africa carries the greatest burden of the epidemic. Epidemic in Asia have remained relatively stable and are still largely concentrated among high risks group. Conversely, the number of people living with HIV in the Eastern Europe and Central Asia has almost tripled since 2000.

AIDS in India

India has parched on the top of an AIDS volcano. At the beginning of 1986, despite over 20,000 reported AIDS cases worldwide. While India has no reported cases of AIDS/ HIV (Ghosh: (1986). In April 1986 India's first cases of HIV were diagnosed among the sex workers in Chennai and Tamil Nadu. By January 1990 there were twelve cases of AIDS detected in foreigners and 32 amongst Indians.

As on 31st March, 1998 out of the cumulative number of 3.29 million persons screamed, 7960 persons were found to be HIV positive. With 74.5% acquiring the infection through hetero sexual transmission. 89% of

the AIDS cases were among the sexually active and economically productive age group (15-50 years with male/female ratio 3:1). In 2000 there were 11125 cases infected by HIV positive (NACO) and in 2001 there were 20304 cases found. By 2002 there were 37566 AIDS cases. Among the states Maharashtra, Tamil Nadu, and Manipur are the states with the highest incidence of infection. From Mumbai and Chennai the migrant workers, truck drivers and paid blood donors are spreading the infection to other areas.

In 2002 the highest number of cases is reported in Tamil Nadu having 16,667 cases followed by Maharashtra with 8039 cases. Gujarat and Andhra Pradesh with 1704 and 1606 cases respectively, Karnataka has 1470 cases of AIDS whereas Manipur has 1172 cases.

AIDS among Children

Hundreds of thousands of children across the world got infected with HIV every year and without treatment die as a result of AIDS. In addition, millions more children who are not infected with HIV are indirectly affected by the epidemic, as a result of the death and suffering that AIDS causes in their families and their communities.

According to UNAIDS there are 2.3 million children aged less than 15 years living with HIV in the world today. The majority of these were infected at birth and most of them will not live to become adults, 570000 HIV positive children died in 2005. In 2008 there are 21 million children living with HIV/AIDS. Every hour, 31 children around the world die because of HIV.

HIV infections among children in India is limited, estimates vary from 1,00,000 to 2,02,000 infected children. According to UNICEF about 2, 20,000 children are born with HIV and about 11,000 die every year in India. Mother to child transmission of HIV accounts vast majority of children who are infected by HIV. Infected women can transmit the virus to her body during pregnancy, labour and delivery and also through breast feeding. Around 20-45% of the children are infected by HIV through breast feeding. It is estimated that 70,000 children below the age of 15 are infected with HIV in India, and 21,000 children are infected every year through mother to child transmission. Apart from the mother to child transmission some children are exposed to HIV through the needles, blood transfusions and also sexual activity.

HIV develops very rapidly among the infants and children and without the treatment. One third of infected children will die of AIDS before their first birthday, another half dying before they attain the age of two. In 2007 there were 270,000 deaths attributed to HIV under the age of 15.

The number of children receiving Anti Retroviral Therapy (ART) has increased significantly in recent years. At the end of 2007 just 200,000 out of 6,90,000 children needing ART was receiving it. It is estimated just 19 per cent of the countries with generalized epidemics provide pediatric HIV treatment in the areas where it is needed (Newell, M. et al (2004).

It is in this background the efforts of Government of India culminated in formulation of policy frame work to combat the problem of HIV/AIDS among children. It is with collaboration with UNICEF, an attempt was made to keep children living with HIV/AIDS to put on the agenda of the National AIDS Control Plan III. The aim is to prevent parent to child transfer of the disease, and provide care and medical treatment to children infected with HIV/AIDS.

HIV/AIDS in Karnataka

Karnataka has been identified as one of the six HIV high prevalence (more than 1 per cent of ante-natal mothers and over 5 per cent of STD patients positive for HIV) states of India as per the state-wise prevalence of HIV in 2003. Of the total number of 1, 03, 857 AIDS cases reported in the country till July 2005, 2,343 cases have been from Karnataka, accounting for 2.25 per cent. A comparison with other HIV high-prevalence states (2005) shows that the prevalence rates in STD clinics as well as among the attendees of ANC are the second highest in Karnataka.

According to Karnataka State AIDS Prevention Society, Bangalore, there is compelling evidence to show that the HIV epidemic has been growing over the past decade substantially from 0.2 per cent in 1992 to 22.3 per cent in 2003.

It is clear that the HIV epidemic in Karnataka is distributed throughout the State. The Sentinel Surveillance Data from 2002 shows that the prevalence of HIV exceeds 1.0 per cent in ante-natal clinics attendees predominantly in Northern- Karnataka. However, some central and southern districts also have prevalence of more than 1 per cent.

Based on the Sentinel Surveillance Round of 2002, 16 districts were identified as high-prevalence districts with a mean prevalence of more than 1 per cent. Bellary district is one of high-prevalence districts. Bellary comes under the administrative control of Gulbarga division and development jurisdiction of Hyderabad Karnataka Development Board, Gulbarga. The present paper has been prepared on the basis of the data collected from HIV infected children of Bellary. According to the 2001 Census, the district had a population of 2,027,140 of which 35 per cent were urban and 65 per cent were rural residents. Literacy rate among the population aged 7 and above was 57 per cent: 69 per cent and 45 per cent among males and females, respectively. According to the

Census 2001, around 19 per cent of the total population in the district belonged to Scheduled Castes and 18 per cent belonged to Scheduled Tribes, 37 per cent of the population were children (0-14 years).

In Bellary district, 1.18 per cent of the population in the age group 15-49 was infected with HIV. HIV prevalence in urban areas was higher than that in the rural areas (1.36 per cent compared with 1.05 per cent). Similarly, HIV prevalence was slightly higher among males (1.24 per cent) than females (1.13 per cent). HIV prevalence was higher among women whose marriage was dissolved than those currently or never married. HIV prevalence was highest among those respondents living in the poorest households, those who are literate but not completed primary school, those who are engaged in business, and respondents aged 30-39 years.

II. METHODOLOGY

The paper is based on the data collected from 100 HIV infected children covered by an NGO known as Nithya Jeevana in Bellary district, Karnataka. "Nithya Jeevana Network of Positives" was founded in October 2004 and registered under the Karnataka Societies Act 1960 in January 2005. It is a network of people living with HIV/AIDS in Bellary district, with vision of 'Every person living with HIV/AIDS leads a quality and joyful life and a mission to improve the quality of life of people living with HIV/AIDS along with orphans and vulnerable children in Bellary district'.

Almost 250 HIV/AIDS infected children from the district come under the National Pediatric HIV/AIDS initiative. Out of this a sample of 100 children were selected, on the basis of random sampling method utilizing lottery technique. The primary data were collected with the help of an interview schedule.

III. OBJECTIVES

1. To trace the history and prevalence of HIV/AIDS – Global and Indian Scenario in General and Karnataka in Particular.
2. To probe into socio-economic background of the infected children.
3. To ascertain health problems those are specific for the infected children.
4. To assess the care and support available to the infected children.

IV. RESULTS AND DISCUSSION

In this section the results pertaining to socio-economic profile and family background, their health status, care and support of the HIV/AIDS infected children are given.

Socio-Economic Profile

The socio-economic background of the HIV infected children has its bearing on their health status, their care and support. There are nearly 54 per cent of the infected children who were females and 46 per cent were males who were all infected through their parents. Nearly 81 per cent of infected children belonged to the age group of 4 to 12 years and only 9 per cent belonged to the age group of 12 and above. The respondents were almost equally distributed between rural and urban area, (i.e. 52 per cent urban and 48 per cent rural) which nullifies the National statistics that HIV/AIDS is more of an urban phenomenon. 69 per cent of the infected children profess Hindu religion, 26 per cent were Muslims. Among Hindus 86 per cent were SC's and ST's and other backward caste groups. Majority of parents were illiterate and belonged to the lower economic group and working as labourers. Nearly, 45% of children are attending school and 30% have dropped out of school.

Health Status

The effects of the HIV/AIDS epidemic on children are manifold. Hundreds of thousands of children every year are infected with HIV, most are left undiagnosed, do not access treatment and die very young. In addition, they have weakened immune systems and frequently prone to mumps and chicken pox. It also happens that when children test HIV positive, they do not return to a health facility to receive treatment. This lost to follow up is due to stigma and counseling challenges, poverty to buy medicines. Hence information about their health status such as their height and weight, CD4 Count, their place of treatment, number of visits' to the hospital, availability of medical facilities, taking ART, opportunistic infection, their treatment is given.

It is noted that HIV infected parents with malnutrition adversely affect the health of children and may result in stunted growth. Hence information about height and weight by age of the respondents is given in Table 1.1 and 1.2

Table 1.1 Distribution of Respondents by Heights and Weights

Age-group	Less than 100	100-119	120-139	140-169	Total
1-4 years	20	02	02	00	24
5-8 years	01	30	05	00	36
9-12 years	00	15	16	00	31
12 and above	00	03	05	01	09
	21	50	28	01	100

Table 1.1 exhibits that nearly 21 per cent of the children have height less than 100 cms and 50 per cent have between 100-119, and 28 per cent of them have height between 120-139 cms and only one child is more than 140 cm. Hence majority of the children appeared to be short with their age when compared to the normal children.

Table 1.2 Distribution of Respondents by Age Weights

Age group	Weight in Kgs				
	10-19	20-29	30-39	40	Total
1-4 years	18	06	-	-	24
5-8 years	18	16	02	-	36
9-12 years	14	16	01	-	31
12 and above	-	04	02	03	09
	50	42	05	03	100

Table 1.2 reveals that nearly half of the respondents (50 per cent) of different age groups weigh less than 20 kgs. While 42 per cent weigh less than 30 kg, only eight children weigh more than 30 kgs. Hence it is observed that a majority of the infected children are under weight for their age, and looked weak when compared to normal children.

Table 1.3 Distribution of Respondents by CD4 Count

To judge whether an HIV Positive person required treatment a CD4 test was usually carried out, where falling CD4 Count was a sign that HIV was progressing, that immune system was becoming weaker. In healthy uninfected adults absolute CD4 Count was usually between 400-1600 cells per cubic millimeter of blood, whereas HIV positive adults CD4 Counts falls below 350 it is usually recommended that they should start receiving Anti Retroviral Treatment.

Table 1.3 presents data regarding the CD4 test of the respondents. While for 35 per cent of the respondents CD4 Count was between 100-199, and for another 45 per cent CD4 Count was between 200-299, and for an additional 18 per cent of the respondents, CD4 Count was between 300-399 and for the remaining two per cent CD4 Count was below 100.

Particular	No. of Respondents	Percentage
Below 100	02	02
100-199	35	35
200-299	45	45
300-399	18	18
400 and above	00	00
Total	100	100

Table 1.4 Distribution of Respondents by Place of Treatment

Place of Treatment	Number	Percentage
Government Hospital	65	65
Private Hospital	13	13
NGO	22	22
Total	100	100

Table 1.4 provides information about the place of treatment of the respondents. 65 per cent of the respondents went to government hospital for their treatment while 22 per cent of the respondents went to NGO for their treatment and only 13 per cent of the respondents went to private hospital for their treatment.

Table 1.5 Distribution of Respondents by number of visits to hospital in a year

No. of visits to a hospital	No. of Respondents	Percentage
2-3Times	67	67
4-6 Times	31	31
7-8 Times	02	02
8 and above	00	00
Total	100	100

The respondents who were CLHA (Children living with HIV and AIDS) are vulnerable to opportunistic infections from time to time, as their CD4 count comes down, the immune system of the respondents failed thereby paving way for opportunistic infections. It was observed that the use of ART lead to many side effects forcing the respondents to visit hospitals for treatment.

Table 1.5 highlights that majority of the respondents (67 per cent) visited hospitals 2-3 times and 31 per cent visited the hospital for 4-6 times and two per cent of the respondents visited the hospital 7-8 times in a year who were also admitted to the hospital for treatment several times.

Table 1.6 Distribution of Respondents by Test Centre

Test Centre	No. of Respondents	Percentage
Government Hospital	88	88
Private Hospital	12	12
Total	100	100

Table 1.6 depicts the distribution of the respondents by Test Centre. A vast majority of the respondents (88 per cent) tested their HIV status in government hospitals underlying the fact that children belong to lower income family group. While the remaining 12 per cent of the respondents tested their HIV status in private hospital. It was observed that there were neither gender differentials nor class differentials for HIV.

Table 1.7 Distribution of Respondents by Awareness of Disease

Awareness of Disease	No. of Respondents	Percentage
Yes	08	08
No	92	92
Total	100	100

Table 1.7 illustrates the awareness of the HIV among children. Data reveal that an overwhelming majority of the respondents (92 per cent) were unaware of the disease whereas only 8 per cent of the respondents were aware of the disease. The latter consisted of children who were mainly orphans or children who experienced discrimination from others.

Table 1.8 Distribution of Respondents according to Requirement of Medical Facilities

Requirement of Medical Facilities	No. of Respondents	Percentage
Yes	42	42
No	28	28
No Idea	30	30
Total	100	100

Table 1.8 explains that requirement of Medical Facilities to the infected children who sought them. The data show that 42 per cent of the respondents stated that they got the required medical facilities, another 30 per cent of the respondents had no idea of such facilities being available, while 28 per cent of the respondents who said no to the existence of these facilities were generally illiterate and ignorant.

Table 1.9 Distribution of Respondents by Taking ART

Particular	No. of Respondents	Percentage
ON ART	26	26
NON ART	49	49
PRE ART	22	22
NO Idea	03	03
Total	100	100

HIV infection is not the end of life, for people can lead a healthy life for a long time with the aid of appropriate medical care; by undergoing Anti Retroviral Treatment at right time to effectively suppress replication of virus.

Table 1.9 provides information about the number of respondents who are ON ART. Nearly half of the respondents (49 per cent) were NON ART, 26 per cent of the respondents were ON ART, 22 per cent of the respondents were PRE ART and three percent of the respondents stated that they had no knowledge of ART.

Table 1.10 Distribution of Respondents by Opportunistic Infection

Medical Problem	No. of Respondents	Percentage
Skin Infection	25	25
Cough and Fever	38	38
Loose Motion	15	15
Stomach Pain	14	14
Joint Pains	02	02
Total	100	100

Table 1.10 illustrates about the opportunistic infections suffered by the respondents. 38 per cent of the respondents were suffering from cough and fever while 25 per cent of respondents were suffering from skin infections. 15 per cent, 14 per cent and two per cent of the respondents were suffering from loose motions, stomach pain and joints pain, respectively.

Table 1.11 Distribution of Respondents by their Treatment

Treatment	No. of Respondents	Percentage
Regular	58	58
Irregular	40	40
NO Treatment	02	02
Total	100	100

Table 1.11 depicts the nature of treatment of the child. While now a days people are becoming conscious about HIV/AIDS yet they failed to provide regular treatment to the child due to poverty. 58 per cent of the respondents underwent regular treatment, 40 per cent of the respondents underwent irregular treatment and two per cent of the respondents were not undergoing any treatment at all.

Care and support:- It was seen that children are not only personally affected by HIV/AIDS but it is also affecting their families and their right to a parental care and affection. UNICEF finds that infection can lead children to drop out of school; infection of parents can lead children to engage in child labour in order to survive. Many children who were orphaned were highly exposed to abuse, exploitation and neglect because of loss of a parent(s) or guardian. They experienced a great deal of social stigma as well as discrimination. This resulted in children being marginalized from essential services such as education and health. We proceed to give the data about the living arrangement of children, attending school and their performance they faced, treatment meted out to them by neighbours and friends, with a view to highlight these problems.

Table 1.12 Distribution of Respondents by Attending School

Particular	No. of Respondents	Percentage
Baby Sitting (Anganwadi)	25	25
1 st -4 th Standard	32	32
5 th -10 th Standard	13	13
Drop out	16	16
Not attending School	14	14
Total	100	100

Table 1.12 presents information about school particulars of the respondents. Nearly 32 per cent of respondents were studying in 1st - 4th standard and 13 per cent of the respondents were studying in 5th- 10th standard. 16 per cent of them were dropped out from the school and 14 per cent were not at all attending school. Poor health and economic conditions were found to be the major problems forced these children to remain absent and out of school.

Table 1.13 Distribution of Respondents by their performance in School

Particular	No. of Respondents	Percentage
Good	17	17
Average	39	39
Poor	14	14
Not Applicable *	30	30
Total	100	100

* Not Applicable refers to those children who are not attending and dropped out of the school.

Table 1.13 reveals the performance of the respondents in the school. Their performance was assessed as good, average and poor on the basis of the results they obtained in the earlier class, i.e. who scored more than 60 per cent rated as good, between 50-59 as average and less than 40 per cent as poor. Accordingly 17 per cent of children performance was good, 39 per cent was average and 14 per cent was poor.

Table 1.14 Distribution of Respondents by Treatment of Neighbours

Neighbour's Treatment	No. of Respondents	Percentage
Good	87	87
Sympathetic	10	10
Bad	03	03
Total	100	100

Table 1.14 highlights that a large majority of respondents (87 per cent) felt that their neighbour's treatment towards them was good as their parents often never disclosed about their disease, another 10 per cent of the respondents stated their neighbours were sympathetic towards them. In such cases the neighbours who knew about their disease. While only three per cent of the respondents remarked that their neighbours treatment towards them was bad. Hence they have been facing severe discrimination.

Table 1.15 Distribution of Respondents by Treatment of Friends

Friends Treatment	No. of Respondents	Percentage
Good	75	75
Sympathetic	10	10
Bad	05	05
Total	100	100

Table 1.15 illustrates the nature of treatment of friends towards HIV infected children. Data reveal that three-fourth of the respondents (75 per cent) reported that their treatment of their friends towards them was good, as the latter did not differentiate against other normal children. 10 per cent reported that they were sympathetic towards them whereas five per cent of the respondents stated that their friends treated them badly and did not like to mix and play with them.

Table 1.16 Distribution of Respondents by the additional needs

Particular	No. of Respondents	Percentage
Financial Help	90	90
Counseling	02	02
Life Skill Training	08	08
Total	100	100

HIV is a life threatening disease. Consequently it imposes heavy pressure on the finances of the family. If the family happens to be is BPL one, the problem is still worse. They require and deserve all kind of help both from Government and NGO's.

Table 1.16 demonstrates that 90 per cent of the respondents were in need of financial help/assistance especially in the form of AIDS Orphans Pension, National Insurance Scheme to cope with the expenses of treatment. The remaining respondents (10 per cent) stated that they were in need of counseling and life skill training facilities.

V. SUMMARY AND CONCLUSION

The paper has analyzed the information collected from 100 HIV/AIDS infected children of Bellary who comes under the protection of an NGO known as The Nithya Jeevana Network of Positives. The findings of the paper suggest that HIV/ AIDS infected children are found to be socially and economically backward who are equally distributed irrespective of gender and residence- rural or urban. They were in poor health status in terms of height and weight when compared with the normal children of their age. Majority of the children have CD4 Count below 400 indicating weaker immune system that made them to suffer from various opportunistic infection. Poverty of the children invariably made them to visit government hospitals and NGO's in some cases to get free medical treatment. Often the government hospitals have become test centre for majority of the children.

It is however interesting to find the fact that children in the age group of 4-12 are neither aware of the disease nor its resultant social discrimination. Nearly half of the respondents lacking the knowledge of required medical facilities Anti Retroviral Treatment. This is indicative of the fact that despite of the institutional support through Government's and NGO's in combating HIV/AIDS among children, due to poverty the parents failed to provide regular and safe treatment for their children.

As regards care and support, it suggests that children living with HIV/AIDS have been facing with some discrimination by their neighbours and friends. In majority cases the poverty of the children did not disclosed the disease with the fear of the stigma attached to it. Poor health, poverty and discrimination have made many children to remain absent from school. Since most of the children were poor, they need all sorts of help especially financial help from the government and the public.

Hence the following suggestions may go a long way in improving the health seeking behaviour of the HIV/ AIDS infected children.

1. Family Centred Approach - Families are often a more long-term stable form of care for a child than an institution or care-programme. Supporting a family holistically can be the best way to ensure a good quality of life for the child. Social protection schemes that provide external assistance to poorer HIV infected families would play a valuable part of improving the lives of children affected by AIDS. By reducing a household's economic vulnerability children benefit from better nutrition, the opportunity to go to school instead of work and better access to healthcare. Moreover, children benefit from the emotional support that is provided through the family.
2. National Strategies - Government-led initiatives that include providing vulnerable children with some sort of external support such as greater access to drugs and ART, appropriate tertiary facilities, since prevention is better than cure. Care should be taken to prevent mother to child infection.
3. The government hospitals should be strengthened in terms of infrastructure and facilities. Besides free counseling, free checkups, free medicine there should be compulsory monitoring system and follow up in order to keep such children healthy and active.
4. Media and Propaganda – There is a need to change the attitude of the people towards the HIV infected children. As the HIV/AIDS infected children are marginalized due to social stigma and discrimination. This can be effectively done through the wider publicity and propaganda by media.
5. NGO's should also take interest in changing the mindset of HIV parents and children. Efforts should be made in turning their mind from marginalization to education.

Hence the life of HIV/AIDS infected children become better only if state, family and society dispose their responsibilities and respect the National efforts and universal rights of the children. State must demonstrate leadership by creating effective accountability framework and devising comprehensive and convergent policies.

The family as a basic institution must ensure emotional support besides improving the lives of children. Finally the society as a whole must be honest in treating such children.

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